

1500 Guidelines and Growing: the UK database of clinical guidelines

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Introduction

The National electronic Library for Health (1) (NeLH) is one programme within England's National Health Service (NHS) Knowledge Service. This service defines three types of knowledge (2):

- knowledge derived from research – evidence
- knowledge derived from routinely collected or audit data – statistics
- knowledge derived from the experience of patients and clinicians.

A major evidence resource within NeLH is the *Guidelines Finder* (3). This is a database of UK clinical guidelines available in full text on the Internet. This facility was commissioned from the University of Sheffield Health Sciences Library in 2002, which already had set up a guidelines database as a local service. At present, the service has identified 1500 guidelines and it is growing. This paper will outline:

- the historical and political dimension of guidelines
- the nature of guidelines as a mechanism to ensure clinical effectiveness in practice
- the maintenance and organisation of the *Guidelines Finder*
- its usage and users
- and some lessons from a local library offering a national service

Historical and Political Dimension of Guidelines

Clinical guidelines have existed for centuries and the Hippocratic oath might be considered to be the first medical guideline. The many quotable aphorisms from William Osler (1849 – 1919) are also considered as guidelines. But the number of real guidelines has grown since the methodology of randomised clinical trials (RCT) was applied to diagnosis, prognosis and therapeutics from the 1940s and the ascendancy of evidence-based practice and systemic reviews over the last twenty years. The 21st century clinical guideline has four roles (4):

1. to serve as a written document in which available scientific knowledge is synthesised
2. to be an instrument for communication between the scientific community and practitioners
3. to transform notions of scientific truth into action
4. to provide a mechanism for the efficacy and effectiveness in medicine.

One of the main guideline producers in the UK gives this definition - "Clinical guidelines are systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances. Guidelines provide recommendations for effective practice in the management of clinical

conditions, where variations in practice are known to occur and where effective care may not be delivered uniformly” (5).

This definition indicates that the use of clinical guidelines has impact at four levels. At the patient level, where evidence-based interventions will have positive results in health status. At the health personnel level, where decision support is available, time will be saved and knowledge is kept up-to-date. At the organisational level, where there will be efficiency in resource utilisation including decreased admission rates and length of stay. At the political level, where healthcare quality and equity (and costs) will be an imperative.

Within the UK, where the National Health Service is funded through taxpayers, the political dimension relates to balancing the expectations of customers, the increasing choice of medical interventions and the limitation of resources. NICE (National Institute for Health and Clinical Excellence) is one response from the UK Government to address this dilemma. NICE, an independent agency set up in 1999, has now published more than 40 clinical guidelines, 90 technology appraisals and over 100 interventional procedures. The recommendations from technology appraisals are mandatory for NHS Trusts in England and Wales and have to be implemented within three months, monitored by the Department of Health (6).

The Nature of Guidelines as a Mechanism to Ensure Clinical Effectiveness in Practice

The NHS has suggested that there are five reasons for choosing an area in which to develop guidelines (7):

1. where there is excessive morbidity, disability or mortality
2. where treatment offers good potential for reducing morbidity, disability or mortality
3. where there is wide variation in clinical practice around the country
4. where the services involved are resource-intensive – either high volume and low cost or low volume and high cost
5. where there are many boundary issues involved, sometimes cutting across primary, secondary and community care, and sometimes across different professional bodies.

This view comes from a national (cost effectiveness) perspective, which needs to be balanced with a medical (clinical effectiveness) perspective. For individual health professionals, guidelines will help them to identify and implement appropriate patient decision pathways. In the case of generalists, who may struggle to keep up to date with the increasing volume of new information, guidelines will be particularly useful when uncommon conditions are presented (8).

Many guideline publishers (9, 10) publish their guideline development processes, but some do not, so it is difficult to confirm that their process is actually evidence-based. It is suggested that a model process should include:

1. Explicit criteria for selection of topics (to meet clinical needs or political imperatives).
2. A multidisciplinary team formed to develop the guideline.

3. A systematic review of the literature undertaken and results critically appraised, by appropriately trained staff. There is an extensive range of literature, some of which *Guidelines Finder* has identified (11), documenting how this part of the process is undertaken in order to ensure that recommendations are explicitly linked to the supporting evidence. This includes checklists, evidence tables and judgement forms
4. Stakeholders consulted to review the guideline recommendations.
5. An implementation strategy to ensure that guidelines get into practice.

Although it is important that the development process for guidelines be rigorous, the real impact of guidelines on practice is heavily dependent on an effective implementation strategy. It needs to be noted that most guidelines are owned by professional bodies, which they issue as *advice* to their members. Only a small proportion of guidelines published are mandatory for the medical community. Responsibility for the implementation of guidelines in England rests with Health Authorities, NHS Trusts, clinicians, patient representatives and professional bodies, so it is a complex equation. Factors that impact on the implementation of mandatory NICE guidelines relate to (12);

- funding implications
- supportive culture within the clinical team
- strength of the evidence underpinning the recommendations
- interpretation of that evidence within the local context
- whether professionals had previously identified areas where practice needs to change.

These factors will also apply to discretionary guidelines. Within Sheffield, a Ten Stage Model for local NICE guideline implementation has been designed and has been commended nationally. The *Guidelines Finder* has also identified core research relating to guideline implementation (13).

Despite implementation challenges, research on the effectiveness of guidelines on changing clinical practice is positive (14, 15).

Legal implications of guidelines are also important (16). The following quote comes from Department of Health guidelines about drug misuse - "Any doctor not fulfilling the standards and quality of care in the appropriate treatment that are set in these clinical guidelines, will have this taken into account if, for any reason, consideration of their performance in this clinical area is undertaken" (17). Easy access to and retrieval of clinical guidelines by practitioners is crucial and *Guidelines Finder* has a central role in answering this need.

Guidelines Finder: maintenance and organisation

The maintenance of the *Guidelines Finder* is an ongoing task and various mechanisms are in place to ensure that newly published guidelines are identified and added to the database as quickly as possible. Some guideline publishers alert *Guidelines Finder* when new guidelines are published or have a very regular publication schedule, for example NICE tends to publish on the last Wednesday of the month. A number of key websites are checked daily for new guidelines, and these include the Department of Health, NICE and SIGN websites. A rolling, monthly schedule is in place for

checking c.100 other websites, for new content in less regular publishers. The NeLH Specialist Libraries also assist with the process of identifying guidelines that might otherwise have been overlooked, as part of their own content development work and will suggest additions to the *Guidelines Finder* via a web form.

Once new content is identified, which meets the *Guideline Finder* selection criteria (see below), the guideline is indexed on our online database. Each record includes publication details, a link to the guideline itself, a structured abstract (including aims, intended audience, any access issues), keywords and specialty tags. Some guidelines are produced in different formats, for example they may be intended for use by patients, or summarised as quick reference guides, and links to these different versions are also included where this is the case.

NeLH is increasingly managed through a resource management system (RMS), to which the *Guidelines Finder* team have access rights and can update resources and website content directly.

Another important aspect of maintenance is to check that the links to guidelines are still valid and functional, so that users are not faced with dead links or 'page cannot be found' messages. Fortunately, with almost 1500 links to check, this process is now automated (18)! A publication date audit of *Guidelines Finder* content is undertaken each year, in order to remove obsolete, older guidelines. This involves contacting each of the relevant publishers for currency information. Once the audit is complete, those guidelines that are older than five years, but still valid, are flagged in the publication history section of the guideline's record - "Guideline published more than 5 years ago, but publisher has confirmed the guideline's continued validity (date)".

Guidelines Finder users can search for relevant content on the website by using a keyword or specialty search, and results are returned in alphabetical order. Latest additions to the database are listed on the home page and updated monthly.

Guidelines Finder: criteria for selection for guidelines

A clinical guideline must meet **all** of the following criteria to be included in the Guidelines Finder:

1. *The clinical guideline is produced under the auspices of an international or national medical specialty association, relevant professional society or government agency.* See below to see the wide range of organisations which publish guidelines. The *Guidelines Finder* does not index guidelines from local organisations as they often relate to specialist local situations, many are not available on the Internet and, at present, the team does not have the resources to identify and update the thousands of guidelines produced by individual health organisations.
2. *The guideline is produced in the UK, or produced outside the UK by one of the foregoing types of groups and officially endorsed by an authoritative UK organization.* The primary aim is to cover guidelines published for the UK community, but non-UK guidelines, which are seen to fill a gap in the UK

collection, will also be added. NeLH Specialist Libraries are the main mechanism for identifying international guidelines which fill these gaps.

3. *Corroborating documentation can be produced and verified that a systematic literature search and review of existing scientific evidence published in peer reviewed journals was performed during the guideline development.* The *Guidelines Finder* team review the guideline (or the publisher web site) to ensure that it is 'evidence based'.
4. *The guideline has been developed, reviewed, or revised within the last five years.* Currency is important and a 'health-warning' is added if a guideline is older than five years.
5. *The guideline is in English.* It has been decided that the resource will point only to guidelines written in English. Therefore non-UK guidelines written in other languages are not included.
6. *The guideline is available freely on the Internet.* This principle is crucial to the philosophy of the *Guidelines Finder* – knowledge must be accessible freely. Experience demonstrates that the vast majority of guideline publishers wish to make their guidelines accessible via the Internet, but there are a few exceptions to this criteria for key guidelines published only in journals.

Guidelines Finder: who publishes guidelines and guideline formats

Within the UK there are four types of organisation that develop guidelines:

1. Government or Government funded organisations. These include
 - NICE (National Institute for Health and Clinical Effectiveness)
 - Department of Health
 - PRODIGY
 - SIGN (Scottish Intercollegiate Guidelines Network)
 - CREST (Clinical Resource Efficiency Support Team – Northern Ireland)
2. QUANGOs (Quasi non-governmental organisations). These include:
 - Health Protection Agency
 - Foods Standards Agency
 - UK Blood Transfusion Services
3. National organisations which have responsibilities for education or quality assurance of health professionals working in specialist areas. These include:
 - Royal Colleges (Physicians, Surgeons, Nursing etc)
4. National organisations or charities working in a particular clinical disease or condition. These include
 - British Hypertension Society
 - Diabetes UK
 - Meningitis Research Foundation

In August 2005, there were 85 UK organisations which have published guidelines that are included in the *Guidelines Finder*.

The range of formats of clinical guidelines that have been identified is wide. Within the *Guidelines Finder* there are

- major 100 page research reports, which might take two years to prepare (19)
- two page synthesis of a clinical condition which can be assimilated in five minutes by a busy clinician (20)

- algorithms (flow charts) to be used as wall-charts in surgeries (21)
- patient information leaflets (22)
- management guidelines for service improvement (23).

The targeted audience and intended use for these documents will be different and the *Guidelines Finder*, with its structured abstract for each guideline, aims to identify the purpose of the guideline.

Usage and Users

It is not possible to identify individuals who are accessing the Guidelines Finder, or why, on a regular basis. Visits to the site are still increasing with an average of 12,500 visits per month, with a peak of 14,000 visits. It is one of the most visited resources within NeLH.

An evaluation of the service (24) was undertaken by the Centre for Information Research, University of Central England in Birmingham in 2004, which included three online surveys of potential UK users (174 responses). Ten follow up telephone interviews were also undertaken. They identified a wide range of reasons for using the Guidelines Finder:

- for study (45%),
- to support local management decisions on guideline development and implementation (43%)
- to support a specific patient problem (36%)
- for research activities (28%)

In response to a question asking if using the Guidelines Finder ‘had enhanced patient care’, 43% said yes, 38% were not sure and 15% said no (4% no response).

User groups were:

- nursing staff (30%)
- medical staff (25%)
- Allied health professionals (17%)
- Information professionals (12%)
- Managers/administrators (10%)

Internet analysis identified that 82 UK and 51 non-UK organisations had linked to the Guidelines Finder site from their own web sites. The non-UK country with most links to the *Guidelines Finder* was Spain.

The main recommendation from the evaluation report related to promotion to address low awareness of the service. Two of the online surveys identified non awareness at 77% and 37%. 14,000 visits per month is obviously only the tip of iceberg demand! Promotion of web sites is a known marketing dilemma and future service actions will include:

- attending relevant conferences (posters, display stands)
- targeting health librarians and information professionals
- press releases to relevant journals.

Lessons from a local library offering a national service

As mentioned, this national resource is delivered by a University health sciences library. It is exciting for local librarians to work at the national level and the team feel

that they are adding knowledge to the 'knowledge base'. Management of many of the NeLH resources are devolved, with 16 Specialist Libraries, so there is a community of information professionals contributing to a national service. The public relations dimension for the University of Sheffield Library is positive and it is seen as innovative. Particular lessons are:

- there are benefits to the local team as additional knowledge and skills learnt can be applied to the local environment,
- but there will be risks to the local team if the contract is not renewed and experience and knowledge is lost,
- the Sheffield NHS Trusts see the Health Sciences Library more relevant,
- the specification and price of the Contract needs to be negotiated carefully so the local service is not disadvantaged.

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